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ABSTRACT

This paper reviews the literature examining the lifelong challenges to family members represented by the birth of a child with severe disabilities. The paper addresses issues of family life, the systems that affect families, and current and future concerns related to having a child with severe disabilities. Studies addressing families of infants, toddlers, and preschoolers with disabilities are reviewed first. The emotional stages that a family experiences when first told that a child has a diagnosis of a disability are discussed, along with factors that influence how and when parents reach the acceptance stage. Factors include disability area and degree of disability, family characteristics, and the strength available from the family system. The daily issues families of young children with severe disabilities face are addressed and the different systems families encounter are described. The paper then discusses the secondary transition years, the daily issues faced by families of adolescents with severe disabilities aging out of the educational system, and the systems they encounter. The paper concludes that system involvement, issues of concern, and the daily life of families having a child with severe disabilities show little change from the early years to the secondary transition years. (Contains 27 references.) (CR)

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FAMILIES AND CHILDREN WITH SEVERE DISABILITIES:

DAILY LIVES, SYSTEMS, AND CONCERNS

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Abstract

The birth of a child with severe disabilities presents many new and lifelong challenges to family members and caregivers. This paper addresses issues of family life, the systems that affect the families, and current and future concerns related to having a child with severe disabilities as reflected in the literature. Studies addressing (a) families of infants, toddlers, and preschoolers with disabilities, and (b) families of secondary-aged children who are "aging out" of educational services indicate that families deal with the same issues regardless of the age of the child.

FAMILIES AND CHILDREN WITH DISABILITIES:

DAILY LIVES, SYSTEMS AND CONCERNS

by
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The birth of a child with disabilities or one who is at risk for developing difficulties presents many new and lifelong challenges to family members and caregivers. This discussion will address issues of family life, the systems that affect the families, and current and future concerns related to having a child with severe disabilities as reflected in the research literature. Studies addressing (a) families of infants, toddlers and preschoolers with disabilities, and (b) families of secondary-aged children who are "aging out" of educational services indicate that families deal with the same issues regardless of the age of their child.

The Early Years

With advances in medical technology and higher survival rates of premature infants, the prevalence of children with developmental delays is increasing. Although many pre-term infants experience only mild delays in development, others will exhibit substantial limitations, delays, and/or chronic illness that affect not only their lives but also their families. Recent articles indicate that one in 20 preschoolers has vision problems, almost five percent of children have learning disabilities, and one out of 500 Americans may be affected with autism (Wingert & Noonan, 2000). The numbers of technology-dependent (e.g., ventilators, intravenous nutrition, intravenous drug therapy) children is at a high. Although later accidents, secondary trauma, and maltreatment contribute to the total numbers in this population, the majority of severe disability factors tend to occur in the first three years of life.

When a family is first told that a child has a diagnosis of a disability, they experience a wide range of responses called the "stages of grief" (shock, disbelief, and denial; anger and resentment; bargaining; depression and discouragement; acceptance) or stage theory response (Kubler-Ross, 1969). Although these stages provide a guide to describe what families may be feeling, recent research has indicated that passages through the stages of grief are cyclical rather than sequential in nature. Howard, et al. (1997) suggests that grief like any life passage does not indicate dysfunction but rather normalcy. Turnbull and Turnbull (1997) discuss a variety of factors that influence how and when parents reach the acceptance stage. These factors include disability area and degree of disability, family characteristics (e.g., size, culture) and the strength available from the family system. With the birth, or the diagnosis, of a child with a disability, come increased needs, responsibilities, and demands on the family system (Martin, 2000; Martin, Brady, & Kotarba, 1992). The Individuals with Disabilities Education Act (IDEA) ensures that all children and youth with disabilities in the United States access a free appropriate public education. The regulations implementing Part B and Part C of IDEA '97 (P.L.

105-17) relate to preschoolers with disabilities from three to five and infants/toddlers with disabilities and their families respectively. Services include evaluation, determination of eligibility, individualized family service plans (IFSP), service coordination and early intervention services. Initially, families were discussed in relation to a support model of services across the life span of the child (Fewell,1986). More recently, services for families of children with disabilities (Turnbull & Turnbull, 1997) are viewed in terms of family life cycle theory within a framework of family-professional collaboration and family empowerment. For two generations research has looked at families having a child with a disability (Krauss, 1997). As a result, parent involvement is now widely accepted as a necessary component in quality services for young children with disabilities (Bailey et al., 1998).

The Daily Lives

For families of young children with severe disabilities, everyday life is dependent on the status of the child. Therapy treatments, medical appointments, medication, feeding, nutritional requirements, positioning and medical care often comprise the majority of daily time (Knoll, 1992; Martin, et al. 1992). Daily care issues include 24-hour-a-day monitoring of the child and may involve re-occurring crises of extraordinary intervention almost monthly. The routine maintenance and ordering of equipment related to health needs (e.g., ventilators, intravenous feeding, tracheostomies, mobility, colostomies, ostomies, etc.) require medical record keeping, insurance submissions, and the use of valuable time. The home environment becomes an all supportive one with its primary purpose to ensure the health and safety of the child. Examples include: the maintenance of back up batteries for respiratory therapy, ventilators and communication devices; the consistent placement of furniture to allow for the child's exploration and removal of floor "hazards" (shoes, books, purses, etc.); the continuous sound of the air filter machines; dining room tables are record keeping centers stacked with medical files and insurance forms; refrigerators are sites for posted emergency procedures, daily feeding schedules and recordings of fluid intake and output. Families develop complicated schedules to address the needs and responsibilities of the child as well as the daily living needs of the family. Duties are relegated to make the most of valuable time. Grocery shopping is done after 10 PM when the lines are shortest. Laundry is done continuously by the person at home. Shopping is done late at night on the internet. Dishes and silverware go back and forth from the table to the dishwasher and never see the inside of a cupboard (Martin, 2000; Martin, et al. 1992).

Families make decisions affecting daily life as a result of the needs of the child. In a recent study of grandparents and their involvement with a child with a disability, two major decision areas were identified: (a) daily living and (b) division of duties. The three families in the study made a decision to live intergenerationally as a direct result of the diagnosis of the child's disability and related needs. The decision to divide child related responsibilities and duties is determined by the parent(s) and assigned to the grandparents. In each case, the parent(s) maintain all aspects of child rearing and daily life decisions related to the child with disabilities. Intergenerational families have meals

together and coordinate the child's daily care needs and weekly appointment schedule (Martin, 2000).

The Systems

The neonatal intensive care nursery. Most often the parents' first relationship with the child is in the intensive care nursery of a hospital. Infants are sometimes in the hospital nursery for months. Parents struggle to maintain jobs and the daily lives of other children while attending to the infant in the nursery. Many refuse to leave the child and remain for weeks around the clock in a vigil of dedication. One of the first decisions most families make is to purchase a medical dictionary to assist them in understanding the complex terminology used by the child's specialists. Although a more relationship-focused intervention has been advocated (Able-Boone, 1996; Grunwald, 1997), families continue to report feeling left out of the loop of understanding the child's condition (Martin, 2000). The neonatal intensive care experience impacts family dynamics and the usual coping strategies are sometimes inadequate to deal with the stress of the situation (Able-Boone, 1994). Years later, families recount this experience and many cannot tell their story without an intense expression of emotion. Families compile photograph albums of the child's life in the nursery. These albums are reported to be a reminder of the strength and determination of the child to live through the medical ordeal (Martin, 2000; Martin, et al. 1992).

The service system. With the infant's final arrival home, families report nervousness at facing the task of caring for the child independently. Although nursery personnel provide training on how to care for the child before discharge, the reality that daily medical care now rests on the family is daunting (Martin, 2000). Families now must confront the health care needs of the child and begin the process of early intervention services. Acceptance of agency services is a difficult decision; it marks the family's recognition of a possible life long disability. Early intervention services are most often provided in the home but may also be provided in child care settings. One mother said that for the first few months she was exhausted from cleaning the house for the interventionist's visit each week and often cancelled rather than clean. She said she had always been so proud of her home. Now she struggled to accomplish the day-to-day housekeeping and cooking. It was only as the infant grew older and his delay more evident did she welcome the interventionist back and finally gave up on the idea of having a showcase home. One family reported that because of the health demands of the child, there were always at least two service personnel in the home during the day and at least one at night. Another family reports that the home service personnel were viewed as family members and most were privy to what she called family secrets (Martin, 2000). Factors contributing to under utilization of early intervention services by families is a concern. Evidence indicates that the assignment of the primary service provider to a family is a critical component of utilization of services (Kochanek & Buka, 1998).

The educational system. On the child's third birthday, services from early intervention agencies cease and the child enters the local educational system. Although many children who receive early intervention services go on to attend community

preschools and the kindergarten classroom, most children with more severe disabilities enter preschool programs for children with disabilities. Although transition planning begins six months earlier, going from home services to school based services is as traumatic for parents as the neonatal nursery experience. Most families do not expect to put their child on a school bus at age three. Families report following the bus each day to school. After three years of daily care, it would not be unusual for a parent to feel a sense of freedom, however what they report is a recurring and profound fear and sense of loss. Their child has left the safety of the home (Martin, 2001).

The Secondary Transition Years

Each year, in the United States, more than 300,000 special education students leave high school by graduating or "aging-out" (West, Corbey, Boyer-Stephens, Jones, Miller, & Sarkees-Wircenski, 1992). "Aging-out" is a term describing the time when a student reaches the age of 21 (or age 22, if their birthday falls with the school academic calendar year) and is no longer eligible for school services.

This transition from school to the adult world represents one of the most stressful periods in the lives of these children and their parents. The adaptation to having a child with severe disabilities is easier when the child is young, but with the aging process, this adaptation becomes more difficult, as concerns for educational programming, medical intervention, and community activities constantly appear and reappear (Heller, 1993; Sartelli, Turnbull, Lerner & Marquis, 1993).

According to Johnson, Bloomberg, Lin, McGrew & Bruininks (1996), most students between the ages of 18-21 served in public schools have more substantial levels of disability, which require significant extended educational services. Included in these numbers are students, who, because of their severe cognitive, medical and physical disabilities, require extensive personal care, and/or constant supervision or total personal care with intense supervision.

When these students leave high school, they are not apt to go to residential or group homes, because of prohibitive cost, or the lack of the appropriate level of care. Rather, these students will remain at home. Some 1.89 million of 3.17 million persons with developmental disabilities in the U.S. population in 1996 were receiving residential care from family caregivers (Braddock, 1999).Caring for the adult with severe disabilities throughout their lifetime means high active involvement that can lead to caregiver burnout. Yet, despite the concerns and barriers that these parents face in the transition process, they seem to derive meaning from these circumstances and learn to cope with the stressors in their lives.

The Daily Lives

The appraisal of everyday events and the coping strategies used by the families of children with disabilities are processes that change over time; these everyday experiences are what mediate the major events in these families' lives (Affleck & Tennen, 1993).

They develop a method of functioning, which leads to a sense of family equilibrium. In order to survive, the family must function as a unit; therefore, whenever one part of it, i.e., one member, was affected by a change, all daily routines and family functioning, likewise, changed. This resulted in disequilibrium and made the families search, using a trial and error process, to find a new way of functioning (Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; Martin, Brady, & Kotarba, 1992).

By the time the child with a disability reaches the high school years (age 13-21), this sense of equilibrium is directly related to the life events and transitions, i.e., medical problems, societal prejudices, etc., that the families had weathered throughout the life of their child. They have continuously changed their perceptions of what their child can and cannot do, as they move through these transitions. This family equilibrium can best be demonstrated by the adaptations of daily work schedules of caregivers, as well as the accommodations made by the family to prevent undue stress on the child (Baker & Martin, 2000; Martin, 2000; Martin, Brady, Kotarba, 1992). For example, because a child needs constant supervision, one adult (parent or family member) must be at home with them at all times. This requirement is sometimes met by altering the family's work schedules, with the father working days and the mother working nights. This leaves little or no interaction as husband and wife. To eliminate stress for the child, for example, on vacations, the family makes accommodations. They do not go out to eat in restaurants, because going out in public upsets their child. Or, they may be selective about attending public places, choosing only those places that are accepting of their child and his disability (Baker & Martin, 2000).

While most families of students with disabilities look forward to their children gaining a measure of independence, working and living on their own, families of students with severe cognitive, medical and physical disabilities know that their children will not do this. They will not go to residential or group homes, but will, instead, remain at home. Some 1.89 million of 3.17 million persons with development disabilities in the U.S. population in 1996 were receiving residential care from family caregivers (Braddock, 1999). The decision to keep their child at home now seems to place them at a disadvantage and might even jeopardize their family system (Hayden, et al, 1992). Their daily lives will almost certainly be a constant challenge to maintain their family equilibrium.

The Systems

The medical community. The first professional system that families of children with disabilities usually face is the medical community (Martin, 2000; Martin, Brady, & Kotarba, 1992). Oftentimes, it also becomes the initial focal point of their anger, due to misdiagnoses and treatment of medical conditions and lack of empathy by medical professionals toward their child and their disability. Many parents have been met with professional advice to put their children in institutions or to let them go without treatment and expire; those parents have resolved to keep their children as healthy and happy as possible, and have manipulated their lives to keep their family functioning and intact (Baker & Martin, 2000).

The educational system. During their child's "aging-out", families face losing one major form of support, which is legally entitled, (i.e., the public school), and getting it replaced by a daunting and unknown eligibility system of adult community services (Hayden, Spicar, DePaepe, & Chilberg, 1992). Parental stress also seems to increase in proportion to the child's leaving high school, giving credence to the belief that the school system and its entitlement are one of the family's prime source of stability (Clatterbuck & Turnbull, 1996). Yet, the same school system can be one of the major focal points of anger by the families. Throughout their child's school experience, they may have been met by (1) school administrators or personnel who exhibit prejudices toward their child and their presence in school, or (2) what they deem as a lack of educational services provided for their child, despite their attempts to receive them (Baker & Martin, 2000).

Parents remain the best source of knowledge of the ongoing service needs of their children as they exit from school (Wehman, 1992; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). In order to participate more knowledgeably in this latest transition, they need to be equipped with the necessary information from service providers (Goodall & Bruder, 1986). Yet, parents oftentimes receive little or no information from either the school or adult service providers. At their Individualized Transition Plan (ITP) meeting, to ensure that students have opportunities and experiences during their school years to prepare them for post-secondary environments (regardless if the student remains at home or lives independently), parents report that adult service providers representatives were rarely present , and school district representatives offered little or no information toward planning for their child's future (Baker & Martin, 2000).

The Concerns

At the beginning of life with a child with a disability, the first concern is how to care for the child adequately, while keeping the family functioning successfully as a unit (Martin, 2000; Martin, Brady, & Kotarba, 1992). Through the years, these families learn to develop successful tactics to compensate for the life stresses of the child's disability. After a child with severe disabilities moves from school to adulthood, parents are faced with new prospects for concerns. For persons with severe disabilities, the life expectancy has increased from 18.5 years in the 1930's, to 59.1 years in the 1970's, to 66.2 years in 1993 (Braddock, 1999). Thus, there is a great possibility that they will outlive their parents, and the quality of their future, as related to care and residence, may become questionable.

The second concern becomes how to develop a plan for the child's and the family's future, when little or no information is presented to them by either the educational system or by adult service providers. Some families choose to be proactive; they gather information on their own, develop a support system within their family, and make financial and legal decisions to provide for their child in case they are no longer present to care for them. Others choose a "wait and see" attitude and seem to believe that somehow the adult service providers will be available for help in the future. In any event, the families of children with disabilities continue to bear the weight of the care and future

of their child, regardless of any assistance and information that they might receive from social agencies and public institutions (Baker & Martin, 2000).

Families cycle in and out of the same systems and concerns. As the child ages and the need for community support services increases, availability of services to the child and family decreases. As a result, aging families must continuously expend energies and time to creatively address gaps in community service areas thereby placing increased stressors in lives already filled with disability related demands. Community services which may alleviate some of the stressors, for example respite, have been found to be nearly non-existent (Baker & Martin, 2000). System involvement, issues of concern, and the daily life of families having a child with severe disabilities demonstrate little change from the early years of the child to the secondary transition years.

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